

NEWS

The Newsletter of the Veterans Health Administration's Parkinson's Disease Research Education & Clinical Center Richmond/ Southeast

PADRECC SE: A Successful Multi-disciplinary Clinic

by David X. Cifu, M.D.
Associate Director of Patient Care Services, PADRECC SE
The Herman J. Flax, M.D. Professor and Chairman
VCU Department of Physical Medicine and Rehabilitation

PADRECC Southeast (SE) is proving itself successful as a model multi-disciplinary care clinic. This model incorporates Parkinson's Disease (PD) specialists from neurology, physical medicine and rehabilitation, psychology, neurosurgery, nursing, physical therapy, speech and language pathology, occupational therapy and other areas into a single, focused outpatient clinical setting.

Evaluation of Ionaitudinal Uniform Parkinson's Disease Rating Scale (UPDRS Part III Motor Examination) data from 49 consecutive individuals with PD managed at the SE PADRECC reveals that 74% of patients had the same or improved physical functioning at their follow-up evaluations at 12, 24 and 36 months. This is truly an impressive finding when the "gold standard" for individuals with PD (based on the research of the collaborative Parkinson's Study Group) is to experience a slight annual decline in functioning, even when appropriately treated with medications. The 26% of patients who had a decline over these 1-3 year follow-ups actually did better than they would have been expected to based on these "historic controls". Importantly, even when comparing the overall neurologic status of all PADRECC patients studied, this research demonstrates an average improvement of their neurologic examinations over the follow-up periods.

These findings suggest that the multidisciplinary approach to care, which has been so successful in managing the needs of individuals with brain injury, stroke, spinal cord injury and amputation, may also be the optimal model of care for individuals with PD. Future research may identify specific aspects of this treatment model that are most effective, but most likely it is the integration of the multiple facets that is key.

Summer 2005 issue



PADRECC SE Staff

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From the editor

Greetings! My name is Lynn Klanchar, PADRECC SE's new Associate Director of Education. I've been on the job since February and love my position here at VAMC Richmond. As a RN for many years, I have experience in med-surg, neuro, psych, health promotion, rehab and Navy nursing. All these things bring something I need in this job with veterans and Parkinson's disease (PD). Plus each day I learn more and more about PD. I can relate to what it must be like when you are first diagnosed, or find out a loved one has PD.

As a progressive neurological condition, learning about PD is on-going. I hope you take advantage of support groups as an important part of your treatment plan. The goal is to adapt more positively to the physical, emotional and social changes associated with PD. Support groups help by offering support, guidance, and a good time to get your concerns addressed. At the VAMC, we offer an education session each month (see pg. 11), followed by separate discussion groups for patients & family members that Dr. Richard Browne, a psychologist helps lead. Social time with snacks and a raffle make it a fun & educational activity. Please join us whenever vou can.

April was Parkinson's Disease Awareness Month and PADRECC staff all pitched in for an Open House. Later that week, VAMC Richmond's Medical Director, Mr. Phaup, read a proclamation at our support group.

Change is a constant and PADRECC recently had some staff transitions. Director, Dr. Vince Calabrese has retired. Administrative Officer Paul Marcinko has taken a position with Joint Task Force Civil Support, and Rashelle Brown is doing a clinical rotation in Chicago. Dr. Mark Baron, has stepped up as Acting Director of PADRECC Richmond.

Keep a close eye on the PADRECC SE webpage: www.va.gov/netsix-padrecc/.

More educational links and resources targeted to patients and families will be added soon. I am open to suggestions to this newsletter, the webpages, the support group, as well as educational services that PADRECC could offer. Please talk to me. I am listening. Yours truly,

PADRECC

In 2001, the Veterans Health
Administration (VHA) created six
Parkinson's Disease Research, Education
and Clinical Centers (PADRECC) in an
effort to improve care for veterans
suffering from Parkinson's disease and to
pursue treatments and a cure for this
condition. The centers are located in
Philadelphia, Richmond, Houston,
Portland/Seattle, San Francisco and
West Los Angeles.

Richmond/Southeast

The Hunter Holmes McGuire VA Medical Center in Richmond, VA is home to the PADRECC for the southeastern region of the United States.

PADRECC services: interdisciplinary assessment and treatment, clinical trials, physician consultation, medical management, surgical interventions, neuropsychological services, physical and occupational therapy, speech therapy, nursing services, caregiver resources, educational materials, community education programs and support services.

A **Telemedicine Clinic** is also available for veterans with Parkinson's disease living in the Southeastern region the US who cannot easily travel to Richmond for an appointment.



Hunter Holmes McGuire VAMC 1201 Broad Rock Boulevard, Room 2C-114 Richmond, VA 23249 Phone: (804) 675-5931 or toll-free (800) 784-8381 ext. 5931 Fax: (804) 675-5939

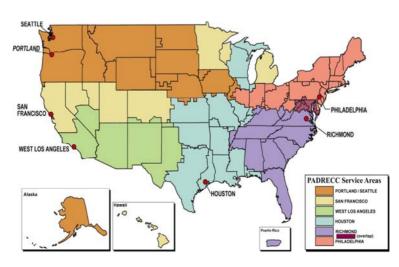
Richmond PADRECC website: www.va.gov/netsix-padrecc/
National PADRECC website: www.va.gov/padrecc

Richmond/Southeast PADRECC



Clinical Care

Recommended Service Areas for PADRECCs



Veterans Health Administration

PADRECC STAFF IN THE NEWS

VCU School Center VCU School Center And School Ce

Dr. Kathryn Holloway

Deep Brain Stimulation Headlines

The Winter 2004 issue of "For Your Health", News and Information from the Virginia Commonwealth University (VCU) Medical Center, spotlighted Kathryn Holloway, MD, Neurosurgical Director at PADRECC Richmond/SE. She is also an Associate Professor, Department of Neurosurgery at VCU. Her work as the lead developer for performing frameless deep brain stimulation (DBS) was explained in the cover story with pictures and an interview. Kelli Massey-Makhoul, RN, Neurosurgical Nurse Coordinator at PADRECC Richmond/SE teamed with Susan Heath from PADRECC SF. They presented a poster that highlighted the difference between frame and frameless DBS at the American Association of Neuroscience Nurses meeting held in April in Washington DC. Surgical intervention called DBS may be appropriate for patients whose medications are no longer effective in controlling the symptoms of PD or if the meds cause severe side effects. Referral Information: please contact Kelli Makhoul at 804-675-5931 or 800-784-8381 x 5931.

Published in PM&R

The research of **Abu A. Qutubuddin, MD** is featured in the April 2005 issue of the *Archives of Physical Medicine* and *Rehabilitation*. His manuscript is titled "Validating the Berg Balance Scale for Individuals with Parkinson's Disease: A Key to Rehabilitation Evaluation". Results agree with other published research in suggesting that Berg Balance Scale may be used as a screening tool and ongoing assessment tool for patients with PD.



Dr. Calabrese (I) with Dr. Qutubuddin (r)



Paul Marcinko at his farewell luncheon

Goodbye to our Administrative Officer

Sadly we bid **Paul Marcinko**, PADRECC SE Admin Officer, farewell in early June. Paul did wonders getting and keeping PADRECC clinical, research and educational operations running smoothly in his time here at Richmond. We are sad to lose him, but congratulate him for being promoted and taking a job closer to his family. His new work is with Joint Task Force Civil Support at Fort Monroe, VA. Best to you, Paul and thanks for all your hard work at PADRECC!

PADRECC STAFF IN THE NEWS

R KINSOL

Becky Martine (I) & Gretchen Glenn (r) of the Philadelphia PADRECC join Lynn Klanchar (c) at the Unity Walk

PADRECCs represented at Unity Walk

Lynn Klanchar RN, Associate Director of Education, traveled to New York City on April 16 for the Parkinson Unity Walk. This fundraising event brings together all the major Parkinson's disease organizations and advocacy groups. Now in its 11th year, the event features exhibits, and a two mile walk around Central Park. PADRECC brochures from all six centers were made available to participants, thanks to Unity Walk organizers and the National Parkinson's Foundation who graciously provided space for PADRECC literature at their table.

Parkinson's Disease Awareness Month

VAMC Richmond and PADRECC SE acknowledged Parkinson's Disease Awareness Month in April. Activities included the first ever PADRECC Open House. This event gave us an opportunity to showcase our strong clinical base of operations, as well as our research projects and educational programs. Inviting the larger community at Richmond VAMC to get to know PADRECC SE staff is important for clarifying PADRECC identity.



Medical staff at VAMC Richmond earned ½ hour of TEMPO credit for learning about PADRECC & PD at the Open House on 26 April



Peggy Roberge, RN

"Rescue"Drug Apokyn Available at Richmond PADRECC

Through the efforts of **Peggy Roberge**, **RN**, Clinical Nurse Coordinator, over 20 Parkinson's patients and their caregivers have been properly trained and are using Apokyn (apomorphine hydrochloride injection) for the acute treatment of episodes of immobility. Apokyn is an injectable drug to be used in times of "hypomobility" or so-called "off periods" when the patient becomes immobile or unable to perform activities of daily living. Approved by the FDA in April, 2004, **this medicine is used in addition to other Parkinson's medications, not instead of them.** Peggy has been a speaker at community meetings for Parkinson's disease including the Melvin Weinstein Foundation Educational Event in Virginia Beach, and the Richmond "Rescue" Summit in May of this year.

APRIL 2005 PARKINSON'S DISEASE AWARENESS MONTH



VAMC Richmond Director, Michael. Phaup(r) with Lynn Klanchar (I) read this Proclamation at April 28th Support Group

Whereas: Parkinson's disease is a progressive disorder of the central nervous system, affecting more than one million people in the United States and an estimated 40,000 veterans; and

Whereas: In 2001, the Veterans Health Administration created six specialty centers to better address the needs of veterans with Parkinson's disease, establishing them at VA medical centers in Houston TX, Philadelphia PA, Portland OR, Richmond VA and San Francisco, and West Los Angeles, CA; and

Whereas: The Hunter Holmes McGuire Veterans Affairs Medical Center in Richmond, Virginia is home to the Parkinson's Disease, Research, Education, and Clinical Center, named PADRECC Southeast, and serves veterans with Parkinson's disease and other related movement disorders in the Richmond Metro area, VISN 6, and the Southeastern region of the United States; and

Whereas: PADRECC

Richmond/Southeast has a strong and mutually beneficial affiliation with Virginia Commonwealth University Medical Center, sharing expertise in clinical care, education, and research for Parkinson's disease and movement disorders; and

Whereas: PADRECC Richmond/Southeast is a community partner with the American Parkinson Disease Association, Inc., National Parkinson's Foundation, and other organizations dedicated to patient and family services, education, and research to improve care and find a cure for this disease: and

Whereas: The world, the nation, and Hunter Holmes McGuire Veterans Affairs Medical Center (VAMC) Richmond observe "Parkinson's Disease Awareness Month" in April 2005; and

Therefore: I, Mr. Michael B. Phaup, Director of VAMC Richmond, in recognition of the indispensable services of the PADRECC Richmond/Southeast to the veterans served by this Parkinson's Disease Center of Excellence, do hereby proclaim April 2005 Parkinson's Disease Awareness Month at the Hunter Holmes McGuire Veterans Affairs Medical Center, Richmond, Virginia.



Social time at 28 April Support Group at Richmond VAMC



PADRECC Staff hosted an Open House on 26 April for Parkinson's disease Awareness Month

Richmond/SE PADRECC Director Retires

Old and new PADRECC staff helped **Dr. Vincent Calabrese** celebrate his retirement in late February 2005. It was an occasion for all to honor his career, to thank him for his dedication to the treatment of Parkinson's disease and his leadership at PADRECC Richmond/SE. Dr. Calabrese had served as Medical Director of the PADRECC since its inception in 2001. He has been a physician for the past 40 years, board certified in Neurology, a Fellow of the American Academy of Neurology, a member of the Parkinson's Study Group, and the International Movement Disorder Society.

Recently I spoke with Dr. Calabrese about his illustrious career. I asked him about his first experiences in neurology and movement disorders. He told me how brain function had always intrigued him. He reflected about one of his early professors, "a great teacher of neuroanatomy" who helped him correlate brain areas with function. As a resident from 1967-70 at Albert Einstein College of Medicine in the Bronx, he had the opportunity to work with Dr. Irving Cooper, who developed thalamotomy for PD patients. Dr. Calabrese was involved in the initial clinical trials for levodopa, now considered the gold standard medication for treatment of PD.

Over the years, Dr. Calabrese dreamed of developing a Parkinson's Disease/Movement Disorder program. In the early 1980's, he pioneered a movement disorder clinic at both Medical College of Virginia (MCV) and the McGuire Veterans Hospital in Richmond. In 1993, a local pharmaceutical company approached him to do clinical trials with a new PD medication. The drug is an agonist medication that utilizes a transdermal delivery system. It is currently before the FDA for approval.

In 2000, Dr. Calabrese left MCV and went into private practice. He began working a shortened week and pondering retirement. At that time, the PADRECC concept was in the proposal stage. Dr. Kathryn Holloway approached Dr. Calabrese about being part of a PADRECC based in Richmond. At first he agreed to just be one of the neurologists, but later was pressed into service to head up the Center as Director. It was a National PADRECC requirement that a Movement Disorder Specialist serve as Medical Director, and Dr. Calabrese's expertise was needed.



Looking back, he says the experience with PADRECC was "tailor made for me". Spearheading a center of excellence for Parkinson's disease and other movement disorders, Dr. Vince Calabrese was able to live out his dream job.

Dr. Calabrese has a reputation as an excellent clinician and earnest practitioner. His humility and rapport with patients is far reaching. He reminds us to "listen to the patients, pay attention to what they tell you". He is most proud of being a part of the system that brought state of the art PD care to the veteran population and helping to establish proper care auidelines for PD. He acknowledges that work needs to be done to more widely disseminate the proper approach of delivering care to Parkinson's patients. Dr. Calabrese will truly be missed in Richmond and the PADRECC Southeast. We are happy that he will continue to serve as an Advisory Board member for the PADRECC.

I ended the interview with a question about retirement life and hobbies. Artwork had always adorned his office, but not everyone knew that he was the artist. "How much painting are you doing?" I asked. Dressed in a knit polo shirt, looking casual and comfortable, Dr. Calabrese smiled, nodded, and responded, "lots!" Happy Retirement Dr. Calabrese. Job WELL DONE!

Interview by Lynn Klanchar, Associate Director of Education

CARING FOR A LOVED ONE?



TRYING YOUR HARDEST and DOING YOUR BEST ARE TWO DIFFERENT THINGS

Family Caregiving...It's Not All Up to You

One out of five adults finds themselves as the designated caregiver for a loved one who can't manage alone. In an era when extended families are supposed to be getting weaker, many families are moving their aged relatives into their homes to care for them. Concerns over nursing home placement coupled with the soaring costs for long-term care are contributing to the trend. It is not unusual for family caregivers to take on more than they can realistically handle, and many have feelings of guilt if they ask for help. Yet, asking for help is often the best thing they can do for their loved one.

If you manage or provide direct assistance to someone who needs help with day-to-day activities because of a chronic condition, cognitive limitations, or aging, you are a family caregiver. Acknowledging your role, being open to solutions, and understanding that seeking help is in the best interest of everyone, are important steps toward re-establishing a quality of life for all.

You are a family caregiver if you provide Activities of Daily Living (ADL) such as helping your care recipient with getting in and out of the bed and chairs, dressing, getting to and from the toilet, bathing, dealing with incontinence or diapers, and feeding.

You are also a family caregiver if you provide Instrumental Activities of Daily Living (IADL) such as providing transportation, housework, grocery shopping, preparing meals, arranging for outside services, managing finances, and giving medications.

Recognizing the "symptoms" of burnout, anticipating needs, and getting assistance, can help families adapt and enjoy the personal rewards of family caregiving. Signs that may indicate a need for help include an escalation in job-family conflicts, family caregiver exhaustion and stress, the disruption of family relationships, prolonged feelings of sadness, and loss of sleep.

The National Family Caregivers Association and the National Alliance for Caregiving invite you to discover new ideas and resources that can help you get help, feel better and do better. To learn more, visit www.familycaregiving101.org, the non-profit Web site made possible by the generosity of Eisai Inc. ©2004 National Family Caregivers Association and the National Alliance for Caregiving

Take the PDQ

(Parkinson's Disease Quiz)

- 1. What does PADRECC stand for?
 - A. Good question. I have been wondering....
 - B. Parkinson's And Disease Research Efforts Comprehensive Care
 - C. Parkinson's Disease Research Education and Clinical Center
- 2. Which neurotransmitter is affected in Parkinson's disease?
 - A. Serotonin
 - B. Dopamine
 - C. Norepinephrine
- 3. Dr. James Parkinson's (1755-1824) essay on "Shaking Palsy" was published in 1817. What day is his birthday?
 - A. April 11
 - B. April 26
 - C. 4th of July
- 4. How many PADRECCs are there in the Veterans Health Administration?
 - A. Six
 - B. Every VISN has a PADRECC
 - C. One
- 5. What is the gold standard medication for treatment of Parkinson's
 - A. L-dopa
 - B. levodopa
 - C. Both A & B
- 6. PADRECC Richmond/Southeast is purely a research center. No clinical services are available to veterans.
 - A. True
 - B. Absolutely False!
- 7. PADRECC schedules visits and treats veterans with other movement disorders, such as essential tremor (ET).
 - A. True
 - B. False

YU2MGL2: J-C' 5-P' 3-Q' 4-Q' 2-C' 6-D' \-Q



"This logo conveys a visual image of a patient constrained by Parkinson's disease moving from slowness, stiffness and low spirits to agility, balance and joy." developed by Eugene C. Lai, MD, PhD, Houston PADRECC

Education Page

EVENTS

FALL SYMPOSIUM - OCT 8 - (tentative date) - Richmond Area - for people with Parkinson's disease & their caregivers. Stay tuned for details.

WORLD PARKINSON CONGRESS (WPC) - FEB 22-26, 2006 — Washington, DC For the first time ever, doctors, researchers, allied health professionals, caregivers, and people with Parkinson's disease will gather in one place to share knowledge, exchange resources, and develop collaborative relationships in order to identify the best treatment practices and to ultimately find a cure for Parkinson's. For people with Parkinson's, the WPC is a unique and practical opportunity to participate hands-on in the global fight against Parkinson's. Learn about helpful therapies, clinical trials, and valuable copina strategies. Discuss workplace and insurance issues, advocacy, and the economics of family care. Exchange information with other people with Parkinson's, physicians, and caregivers who share your interests. To learn more:

Web: www.worldpdcongress.org Phone: 212-923-4700

The PADRECCs and the National VA Parkinson's Disease Consortium are **Organizational Partners** with the World Parkinson Congress



RESOURCES

MIND, MOOD, AND MEMORY – this National Parkinson Foundation (NPF) Handbook is a brand new release! Developed by members of the Philadelphia PADRECC team and published by the National Parkinson Foundation, Inc. It is the first of its kind to deliver patient-centered education on the mental health aspects of PD. It provides comprehensive overviews of depression, anxiety, cognitive impairment, dementia with Lewy bodies, psychosis, sleep disturbances, and careaiver burden. Look for the booklet at the literature rack in the PADRECC clinic hallway or ask the Associate Director of Education for a copy. Or you can order it directly from NPF at their website www.parkinson.org or by calling 1-800-327-4545.

"ASK THE DOCTOR" - The National Parkinson Foundation recently announced the launch of its **NEW** "Ask the Doctor". This service is free of charge and one of many NPF Discussion Forums you can join. Ask any question that you have about PD by email and receive an answer by return email. You will also receive questions and answers submitted by other subscribers. For more information, or to subscribe, visit www.parkinson.org.

PADRECC Richmond/SE STAFF

Our team of caring and qualified professionals consist of a mix of full-time, part-time, government, contract and fee-basis employees. Many staff have academic affiliations at Virginia Commonwealth University (VCU) Medical Center.

Mark Baron, MD, Acting Director Associate Director of Research & Neurologist

Kathryn Holloway, MD

Neurosurgical Director & Neurosurgeon

David Cifu, MD, Associate Director of Patient Care Services & Physiatrist

Helen Fillmore, PhD

Associate Director of Pre-Clinical Research

Lynn A. Klanchar, RN, MS

Associate Director of Education

Peggy Roberge, RN

Clinic Nurse Coordinator

Kelli Massey-Makhoul, RN

Neurosurgical Nurse Coordinator

Abu Qutubuddin, MD, Physiatrist

William Carne, PhD, Psychologist

Vacant, Administrative Officer

Cathy McGrady, Program Support Assistant

Pam Gigliotti, Laboratory Technician

Heather Green, Research Assistant

Eriqua Carter-Hawkins, Data entry

Theresa McGuirk, Research Assistant

Rashelle Brown, Psychiatric Technician

Barbara Epps Volunteer

Parkinson's Disease Support Group

Richmond VAMC Room 2K-113/115

Remaining 2005 AGENDA 4th Thursdays (unless noted*) 1-3 pm Contact: 804-675-6952

July 28 - Managing Medications/Dealing with Emergencies & Hospitalization

Peggy Roberge, RN, PADRECC Clinic Nurse Coordinator

August 25 - My Healthe Vet (The Gateway to Veteran Health & Wellness)
Debora Schumacher, LPN, Patient
Education Resources, Richmond VAMC

September 22 - Strategies for Dealing with Cognitive & Memory Changes

Richard J. Browne, PhD, Psychologist, Richmond VAMC

October 27 - "What Makes a Good Death?"

Marian L. Baxter, MS, MA, RN, CRRN, Clinical Nurse Specialist, Traumatic Brain Injury Case Manager, Richmond VAMC

November 10* - Parkinson's Disease Resources, Organizations & Advocacy

Lynn A. Klanchar, RN, MS, PADRECC Associate Director of Education

December 15* - Holiday Gathering



Parkinson's Support Groups Richmond Metro APDA

3rd Sunday every month – 2 pm

Health South, 5700 Fitzhugh Avenue, Richmond

1st Tuesday every month – 7 pm

Circle Center, Broad Street, Methodist Home Contact: 804-355-5717

Mrs. Kathy Morton, President - 804-730-1336 Mrs. Betsy Roberson, VP - 804-741-5653



PADRECC Mailing List?

If you received this newsletter with a mailing label, you are on our mailing list. If not, and you would like to receive future mailings from the PADRECC, complete this form, detach and mail to Richmond/Southeast PADRECC, Hunter Holmes McGuire VAMC, 1201 Broad Rock Boulevard, Rm 2C-130, Richmond, VA 23249 or call 804-675-6952.



PLEASE PRINT

Name:			
Address:		Apt #	
City	State	Zip	
Phone number: ()		_	
Email address:			



Parkinson's Disease Research, Education & Clinical Center Richmond/Southeast 1-800-784-8381 ext 5931 Hunter Holmes McGuire Veterans Affairs Medical Center 1201 Broad Rock Boulevard Neurology Service #127– Rm 2C-114 Richmond, VA 23249

